



# AzMN News

Arizona Myeloma Network  
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The Newsletter for People Interested in Multiple Myeloma

## Holiday Message and 2006 in Review!

Dear Friends:

*We wish all of you a Happy and Healthy Holiday Season and New Year! We have so many 'old' and 'new' friends to thank and many wonderful accomplishments to look back on since AzMN became a 501(c)3 organization in January, 2006.*

*Thanks to the guidance of our Executive and Advisory Committees, we have become a small, but busy volunteer myeloma organization with several successful events under our belt: Our Indoor Picnic in June with over 50 attendees and volunteers; our 2nd Annual Golf Tournament at the Raven Golf Course, October 5th, with an attendance of over 130 golfers and dinner guests, and partnerships with local programs including the Glendale Public Library, the Challenger Space Center Museum, and a local Glendale shop, the Pink House.*

*We exceeded our fund raising goals, not through grants or major contributions, but by the hard work of volunteers and community partnerships. Most important, we have honored our Mission Statement; Education, Awareness and Advocacy for myeloma patients and families. We are helping to bring together diverse cancer groups, State and local, on behalf of myeloma, and helping to encourage research and interest in myeloma in collaboration with the Mayo Clinic and TGen. We have supported legislation and patients seeking help with resources.*

*We have exciting plans for 2007- more outreach to the underserved: African, Hispanic and Native Americans. A major, State-wide Myeloma Conference in Tucson, and other collaborative seminars in Arizona. Plus, Fun and Fundraising events: our 3rd Annual Charity Golf Tournament, an Art Show/Sale, and Black Tie Dinner and Casino night. We hope many of our sponsors and supporters will join in and bring more friends to join the AzMN team!*

*Thank you all for your interest, participation and support throughout the year.*

Fondly,  
Barbara Kavanagh

## Upcoming Events

### Tucson Myeloma Conference

AzMN will hold the first **Living with Myeloma Conference**, in Tucson, Arizona, Saturday, March 31st, 2007. The conference is a broad based collaboration of cancer resources in Arizona on behalf of myeloma. The committee, led by AzMN, includes staff from: AZ Cancer Center, Sunstone, and the AZ Comprehensive Cancer Control Program. The Medical Faculty is led by Dr. Rafael Fonseca (Mayo Clinic), joined by Dr. Leif Bergsagel (Mayo Clinic), and Dr. John Carpten (TGen).

More details about the conference will be available on our web site in January 2007...**save the date!** - Saturday, March 31st, 8-4:30p.m. at the InnSuites Hotel in Tucson, AZ. Special room rates are available for the weekend and there is no charge for the conference.

### 3<sup>rd</sup> Annual Charity Golf Event

**Golf!** Friday, September 21st, 2007! Put this date on your calendar and Register Early! The **3rd Annual AzMN Charity Golf Tournament** will be held at the **Orange Tree Golf Resort** in central Phoenix. Further details will be available on our web site in January 2007.

### MMRF and Mayo Race for Research

On Sunday, November 19<sup>th</sup> at Papago Park, over 200 walkers/runners, many of them myeloma patients, families and friends, participated in this 5K race. Dr. Fonseca's father and 10-year-old son accompanied a large team of Mayo and TGen runners. It was a bittersweet day,



Dr. Fonseca, his dad, his son and his son's friend

seeing teams of runners with 'memories' of a loved one lost to myeloma. But, hopeful day too, for Jack and Barbara, who volunteered on Sunday, and the other

myeloma patients, to hear Dr. Fonseca, Honorary Race Chairman, talk about the exciting new treatment options and research on the horizon. Thank you MMRF for your important leadership in the Multiple Myeloma Research Collaborative and the funds you raise on our behalf.

## Community Volunteer Partners!

We appreciate our sponsors and community volunteers who have supported us this year. We hope to develop many more partnerships where we work together to raise awareness about myeloma and also help promote these wonderful business people.

### Pink House and AzMN!

Thanks to our volunteers, Sherry Wong (Windermere), and Tiffany Netherlin (Southwest Mortgage), and Danica Coral (Pinkhouse, our Community partner). Pink House was so pleased with the response that they are extending the 15% discount through the Xmas holidays, so you can still go to the store and mention AzMN and get your discount for great Holiday gifts.

### Wine Tasting at Local Wine Shop Helped to Raise Money and Awareness.

Jill Stacey, owner of WineStyles in Peoria, AZ, sponsored a Silent Auction wine tasting gift for 20 guests at our October 5<sup>th</sup> Golf Event, which was purchased and hosted by Barbara and Darwin Huber of Arrowhead Lakes.



Jill Stacey, Barbara and Darwin Huber

AzMN friends and volunteers had a great time and AzMN made many new friends.

### The Volunteer Challenge at the Challenger Space Center Museum

As the keynote speaker at the October 12<sup>th</sup> Volunteer Challenge, Barbara Kavanagh talked to over 100 participants about the importance of volunteering and about the

work being done by an all-volunteer organization, the Arizona Myeloma Network. At the display table for AzMN, were AzMN volunteers Jack Kavanagh, Sherry Wong, and Sherry's husband,



Volunteers Sherry Wong and Jack Kavanagh

Bobby Wong from the Peoria Police Department. The Black Bear Diner provided the raffle gift for this event.

### Sonoita Chili Cook-off

November 12th Chili cook-off at the Sonoita Santa Cruz Fairgrounds, raised several hundred dollars for AzMN. Participating at the cook-off and arranger of the AzMN benefit event was AzMN volunteer and patient, Peter J. Braly. Thank you so much Peter. Your efforts and support are sincerely appreciated.

### Newsworthy

An article by Eileen Roth, about getting the Feds to address the Medical Insurance



Alan Roth, Senator Barbara Leff, and Eileen Roth

coverage gap that is a major problem for many patients throughout the country, will be included on AzMN's website in December. The article relates to AZ Senate Bill #1442 which was sponsored by Senator Barbara Leff and went into effect on October 1, 2006.

### My Multiple Myeloma Diary

*On September 5, 2006, my life changed. I visited Dr. Aurelio Tiro to review a recent blood test which had some irregularities that was ordered by my primary care physician Dr. Ronald Habros.*

*Actually Dr Habros called me 2 times on a previous Saturday and left a voice mail for me to contact him ... and when you get one call, let alone 2 calls on a Saturday from your Doctor, the news is usually not going to be good. Dr Habros indicated*

*that I needed to see a Hematologist and referred me to Dr Tiro. Dr Tiro after reviewing the blood tests said that he thought I had Multiple Myeloma and said that it would be confirmed with a bone marrow sample which he drew from me half an hour later. He then did the Lab diagnosis himself and confirmed that I have Stage 2 Multiple Myeloma. He then ordered x-rays of all my bones. This aggressive "Tiger" of a Physician on that very first visit quickly took action. He set me up for my first monthly Aredia drip the very next day, immediately prescribed steroid pills and set me up for a weekly blood draw and shots.*

*My bone x-rays showed significant lesions on my right and left arm and a large lesion on my right thigh. Dr. Tiro felt radiation treatment would be appropriate and I was referred to Dr. Farley Yang to review my x-rays. Dr. Yang took additional x-rays and felt that radiation treatment should be started. Subsequently the two Drs. discussed my situation and I had my first of 10 radiation therapy treatments the very next day.*

*Dr. Tiro discussed various treatments available and his first recommendation was to prescribe Revlimid for me. Revlimid is, however, quite expensive and my being on Medicare created additional problems...as I immediately sank into the Medicare Donut Hole...since, on an annual basis, the medication costs \$3,300 which must be paid the first month of treatment and my monthly co pay is only \$329. A family friend was kind enough to loan us the first month's amount due of \$3,300 and I started treatment in October. Now I find out that I must come up with another \$3,300 once again in January 2007, as that is the beginning of a new year. So now we are also fighting the "financial war" in order to continue to be able to use this medication. So far, the Revlimid treatment has been effective...lowering my count by 1,200 during my first month. I started my second cycle this past week.*

*The Aredia seems to really do me in for a couple of days after the drip and I lack energy and am quite tired. The first dosage of Revlimid, which I took in the morning, slowed me down significantly. Dr. Tiro suggested that I take it prior to going to bed and I am doing quite well now and have pretty much resumed my activities with my Children with AIDS Project and Tree of Life Art Gallery.*

*At one point, after the first 3 weeks of treatment, I was really wiped out for a*

*couple of days which really concerned my wife Nancy. After thinking about the whole sequence of events and discussing it with Nancy, I really think that it was just the enormity of the personal situation which hit me all of a sudden. Everything had proceeded so fast over the past few weeks that I had really not had time to think about the effect Multiple Myeloma has already had on my life.*

*I attended my first monthly Phoenix support group meeting at the Wellness Community and I am also participating in a weekly on line support group with 20+ other folks around the country.*

*We attended the IMF Symposium this past Saturday, Nov. 4th and it was helpful and especially Dr. Fonseca's presentation. And, we are planning to attend another seminar in LA next February.*

*My wife Nancy has been a real source of love, support and dedication to my wellness and is Numero Uno of my support team and with the support of family, Drs., nurses, extended family, friends and the "Big Guy Upstairs," I accept this "bump in the road" and look to move forward with my many goals and dreams that I have.*

Jim Jenkins

**Editor's note:** Shortly after writing the above article, Jim was admitted to the hospital and on Friday morning, November 17<sup>th</sup>, had a successful heart defibrillator operation. We all wish you the best Jim, and, a healthy recovery.

### General Information

Articles from our readers are welcome and should focus on information directed towards Multiple Myeloma. Editors reserve the right to edit and shorten text as necessary and to refuse article text or advertising in accordance with AzMN by-laws. Articles are due the first week of each month. Please send inquiries to:

Arizona Myeloma Network, 20280 N. 59th Ave, Ste. 115 #448, Glendale, AZ 85308. [azmyelomanetwork@cox.net](mailto:azmyelomanetwork@cox.net)

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